Improving Healthcare Provider's Knowledge and Attitudes About Pain Assessment in Dementia

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Abstract

Background: There is a high prevalence of pain in patients with dementia that is often not properly assessed or recognized which leads to ineffective treatment. Health care professionals across all disciplines are faced with the challenge of assessing pain in older patients with dementia. The research suggests that healthcare providers lack knowledge in pain assessment in dementia, which may lead to ineffective treatment. ***Purpose***: The aim of the project was to implement an educational program to improve knowledge and attitudes about pain and pain assessment in persons with dementia (PWD). ***Methods****:* A single group pre and posttest design was used. The plan, do, study, act quality improvement model was used to guide the clinical question in the proposed project. The participants were healthcare providers in a long-term care and sub-acute facility. Participants completed a knowledge questionnaire before and after the educational program. A 90-minute educational program was delivered in a group session that included training on the use of the behavioral pain assessment tool (PAINAD). Descriptive statistics and t-test were used to analyze the data. ***Evaluation*****:** Chart review was performed 30 days after the educational program to evaluate the use of the PAINAD. ***Results*****:** The findings showed that knowledge on pain assessment in dementia was low among study participants and there was no significant difference in knowledge on pain assessment from baseline to two weeks after the educational program. ***Significance and Implications***: Pain in patients with dementia is under-assessed and undermanaged and is a serious problem in the nursing home. There is a need to provide educational program to enhance pain assessment knowledge with periodic assessment on the use of standardized assessment tool. Increasing knowledge and attitudes on pain assessment and management in PWD will improve quality care among these patients.

Keywords: pain assessment, dementia, PAINAD, pain education

Introduction

Pain, in persons with dementia (PWD), has an increased risk of being under-assessed and undertreated because of a decreased capacity to self -report. (McAuliffe, Brown & Fetherstonhaugh, 2012; Horgas et al, 2009).

Patients with dementia experience a progressive decline in cognition that can cause a decrease in independent functioning (Hurd et al., 2013). Pain assessment in dementia can be complicated because dementia can impair memory, judgment and the ability to verbally communicate (Horgas, Elliott, & Marsiske, 2009).

Pain is a subjective experience, there is no definitive test for pain and verbal report remains the "gold standard" (Horgas et al., 2009). Pain assessment in patients with dementia especially those who are nonverbal remain a challenge.

The literature supports that pain is not well detected or managed in people with dementia. Passmore and Cunningham (2014), encourages pain assessment be based on direct enquiry with the patient but when not possible observational scales are useful.

Effective pain management in patients with dementia is often associated with healthcare providers' knowledge and attitudes that can impact the assessment of pain in older adults with dementia (Long, 2013).

Background and Purpose

According to the World Health Organization (2016), there are 47.5 million people worldwide with dementia with 7.7 million new cases every year, and 50% of those with dementia experience regular pain (Achtenberg et al., 2013). As per the Lewy Body Association (2015), in the United States alone the cost of dementia is 157 billion dollars annually. The total annual healthcare cost due to pain ranges up to $635 billion (American Academy of Pain

Medicine, 2011).

The American Geriatric Society describes pain in older adults as an "unpleasant sensory and emotional experience". Pain in patients with dementia is a significant healthcare problem that can be difficult to assess and manage. Pain in patients with dementia can present as behavioral disturbances like aggression or agitation (Lu & Herr, 2012; Ahn & Horgas, 2013). Dementia may impact the ability to verbalize pain and may impact the management of pain (Achtenberg et al., 2013).

The prevalence and cause of pain in persons with dementia (PWD), is comparable to those people without dementia, however PWD have an increased risk of being under-assessed and undertreated because of a decreased capacity to self- report (McAuliffe, Brown & Fetherstonhaugh, 2012; Horgas et al, 2008).

Reynolds, Hanson, DeVellis, Henderson & Steinhauser (2008), in a study of 551 adults in six nursing homes, found that as cognitive abilities declined, reports of pain decreased and "pain is not properly identified and cognitively impaired residents had fewer orders for scheduled pain medications than did their less cognitively impaired peers" (p. 388).

Pain assessment and management is important because pain can adversely affect quality of life, mood, sleep, nutrition, mobility, cognition, and social interactions in patients with dementia and should be recognized and treated promptly (Lu & Herr, 2012). Communication of needs in dementia may be impaired and this may adversely impact reports of pain because self -report is the gold standard (Lichtner et al., 2014). The inability to self -report may result in ineffective pain assessment and treatment (Horgas, 2012). Kiavar et al. (2016), reported that patients who are unable to self- report such as those with impaired cognition are at higher risk of under-detection and under-treatment of pain. According to the Centers for Disease Control and

Prevention (2010), findings from the National Home Survey 2004 found that twenty five percent of all nursing home residents reported or demonstrated nonverbal signs of pain and forty four percent didn't have pain medication ordered.

The problem of underassessment of pain is significant because inadequate assessment may lead to under-treatment. Under-treatment of pain in dementia patients can result in depression and anxiety, agitation and aggression, sleep disturbance, decreased socialization, impaired movement, and increased healthcare utilization (McAuliffe, et al. 2012).

Because of a lack of knowledge, problems related to memory deficits are inappropriately treated with psychotropics, sedatives and neuroleptics further hindering the treatment of pain (McAuliffe, et al. 2012). The literature supports that the effective assessment of pain leads to effective management of pain and thereby decreasing behavioral manifestations of pain (Ahn & Horgas, 2013).

Ethically, it is important to provide quality care to those patients who are vulnerable because as nurses we are directed by the principle of justice (Herr et al., 2011). In order to do so, the American Society for Pain Management Nursing takes the position that pain should be promptly assessed even in those who are unable to self –report (Herr et al., 2011). Pain assessment in patients with dementia especially those who are nonverbal remain a challenge. Healthcare professionals across all disciplines caring for patients in the long term care setting are confronted with the challenge of identifying pain in patients with dementia.

The literature suggests that health care provider's attitudes and lack of knowledge regarding pain in dementia affect pain management (Reynolds et al., 2008; Achterberg et al., 2013). Burns & McIlfatrick (2015), surveyed 96 nurses across 17 nursing homes and found that nurses had a lack of knowledge of "the use of dementia-specific pain assessments tools for

residents with cognitive impairment" (p. 479). The literature is saturated with data regarding nurses' knowledge and attitudes about pain assessment. There is very little information on other healthcare provider's knowledge and attitudes about pain assessment in dementia.

PICOT Question

The PICOT question was: Will a collaborative pain education program improve healthcare provider's knowledge and attitudes of pain assessment in patients with dementia?

Aims and Objectives

The objectives of the DNP Scholarly Practice Project Proposal were:

- To educate healthcare provider's (nurses, doctors, physical therapists, occupational therapists and certified nursing assistants) through a collaborative pain assessment education program
- To determine if a collaborative education program on pain assessment in dementia can improve healthcare providers' knowledge and improve assessment of pain and pain management in patients with dementia
- To assess the feasibility of implementing a standardize pain assessment tool in dementia in the long-term care setting.

Catalyst for Change

The Nursing Home Quality Initiative and Advancing Excellence in America's Nursing Home Campaign is ongoing and has been a catalyst of change to promote improvement in quality of care for nursing home residents (Long, 2013). One of the quality measures is to

decrease the percentage of nursing home residents with "moderate to severe acute or chronic pain (Long, 2013, p. 221).

"Federal regulations and F-tag F309" (Long, 2013, p. 221), on the Minimum Data Set (MDS) states that staff in long term care facilities must assess and manage pain. The MDS, is a federally mandated, comprehensive questionnaire for clinical assessment of all residents in Medicare and or Medicaid certified long term care facilities, which allows the reporting of patient's pain by verbal reports or behavioral manifestations (Reynolds, Hanson, DeVellis, Henderson & Steinhauser, 2008). This questionnaire is completed by a Registered Nurse Assessment Coordinator (RNAC) and includes quality measures such as pain. According to Reynolds et al., the MDS also assesses the frequency of patients' verbal reports or behavioral manifestations of pain. The MDS assessment is required for all residents in a certified facility upon admission and periodically.

Needs Assessment. A needs assessment was performed during a clinical practicum at the study site that showed that the collaborative facility is not meeting national benchmark as measured on the Minimum Data Set (MDS) for pain reports for patients with dementia. The GAP analysis is seen in **Appendix A**. The RNAC reports that data on the MDS is being "triggered" for patients with moderate to severe dementia in the long- term care. The national average of reports of moderate to severe pain, according to the quarterly MDS 3.0 Facility Quality Measure Report, from 2/01/2016-04/30/2016 is 8%. The facility report is 59.8%. The RNAC also reports that patients who verbally reported pain to her on each assessment did not have routine or as needed analgesic ordered.

The facility does not use a standardized pain assessment tool. In the 120-bed facility, based on a brief chart review, there are approximately 40 patients with a documented diagnosis

of dementia or cognitive impairment. As above there is no standardized tool to assess pain in patients with dementia especially those who are unable to communicate. The nurse manager reports that the staff nurses have a lack of knowledge in regards to identifying nonverbal pain signs in patients who have dementia and are unable to communicate. The GAP analysis identified that pain in patients with dementia is not well assessed, interventions are identified and desired outcomes stated.

The catalyst for change is that pain is under-recognized and there is no standardized pain assessment tool. Thus the implementation of the standardized PAINAD tool will improve pain assessment leading to better management and decreasing pain reports on the MDS.

The clinical question: Is there a difference in healthcare provider's knowledge on pain assessment in dementia at baseline and two weeks after the implementation of a collaborative education program?

Review of Literature

The online literature was searched for articles on pain in patients with dementia, the use of PAINAD and healthcare providers knowledge about pain in dementia. Literature, as well as in a real health care setting, demonstrate that pain assessment is the most important step to a successful pain management.

In people with dementia, the process of communicating pain is compromised because as the disease progress the ability to communicate decrease and they have reduce ability to recall and verbalize a self-report of pain which can result in inaccurate assessment and treatment of pain (McAuliffe, et al. 2012). When self-report is not possible, it is recommended that observation and detection of pain-related behavior be utilized as an alternative approach to

identify pain in dementia (Achterberg, et al, 2013). The American Geriatrics Society (AGS) Panel on Persistent Pain in Older Persons outlined the various areas that should be incorporated into behavioral pain assessments and these includes: facial expression, negative vocalization, body language, changes in activity patterns, changes in interpersonal interactions and mental status changes (Achterberg, et al, 2013, McAuliffe, et al. 2012). Thus, pain assessment in patients with dementia can be challenging, and represents a significant healthcare problem that can be difficult to assess and manage.

According to Achterberg et al. (2013), the ability to verbalize pain may be impaired in dementia. Lighter et al. (2014), reported that self-report of pain is the gold standard, however there may be impairment of communication in dementia that may adversely impact reports of pain. The inability to self -report may result in ineffective pain assessment and treatment (Horgas, 2012). The evidence across studies varied. Ngu et al. (2015), demonstrated the strongest correlation between self reported pain and the observational pain assessment tools, in particular the PAINAD.

Pain Assessment in Advanced Dementia (PAINAD)

There are many observational pain assessment tools available. Across studies, the evidence supports the use of the Pain Assessment in Advanced Dementia (PAINAD) (**Appendix B)**, because of its strong relationship with self –report. Based on the quality, quantity and consistency of the evidence appraised with the Joanna Briggs Institute tool, a linear relationship in the systematic review and four clinical studies demonstrate the relationship between the PAINAD and self -report. This relationship can be extrapolated into definite evidence for recommendations for practice and supports the use of the PAINAD in the assessment of pain in patients with dementia.

Lukas, Barber, Johnson & Gibson (2013), using a quasi-experimental design studied the use of observer-rated pain assessment instruments (Abbey Pain Scale, PAINAD and NOPPAIN), in 60 cognitively intact and 65 cognitively impaired people and found that the instruments improved the recognition of pain, especially in those in dementia. A multidisciplinary team, Apinis, Arcand and Tousignant-Laflamme (2014), studied 59 nursing home residents with limited ability to communicate, to examine if there was agreement between the interdisciplinary evaluation (IE) and two validated observational pain tools the Pain Assessment checklist for Seniors with Limited Ability to Communicate (PACSLAC) and the PAINAD. The Spearman correlation was used and demonstrated a high correlation (r=0.79 [95% CI: 0.67-0.87] between the PACSLAC and PAINAD.

Healthcare Provider's Knowledge

The literature suggests that healthcare providers' beliefs and knowledge regarding pain in dementia are important barriers to pain assessment and management of care in patients with dementia (Zwakhalen et al., 2007; McAuliffe, et al., 2012; Achterberg, et al., 2013; Gagnon et al., 2013).

Questionnaire. A psychometrically sound questionnaire was developed by Zwakhalen, Hamers, Peijnenburg and Berger (2007) to obtain information on knowledge and beliefs of healthcare professionals regarding pain in patients with dementia. The 17- item questionnaire by Zwakhalen et al. (2007), was developed using a cross-sectional design in two nursing homes and completed by 123 nursing staff. The questionnaire, focused on demographic information including sex, age, educational level, number of years of work experience. A principal components analysis (PCA) was performed to refine the questionnaire. The questionnaire uses a five-point Likert scale (1=completely disagree, 2= disagree to some extent, 3=no opinion, 4=agree to some extent and

5=completely agree) with scores ranging from 17-85. As per Zwakhalen et al. (2007, p. 179), "although knowledge and belief are two closely related constructs, the 17 items remaining in the final scale, with the exception of the second factor, mostly measured knowledge". The author's analyzed internal consistency and the Cronbach's alpha of the 17 item total were reported as 0.782 (Zwakhalen et al., 2007, p. 180). Factor structure and internal consistency of each questionnaire item is also reported (p.180).

Healthcare professionals across all disciplines are confronted with the challenge of identifying pain in patients with dementia. According to Zwakhalen, Hamers, Peijnenburg and Berger (2007), healthcare providers in the nursing home have a knowledge deficit when it comes to pain assessment in patients with cognitive impairment. According to de Freitas et al. (2014), in a cross-sectional study of degree of knowledge of healthcare professionals across disciplines, results suggest problems in pain identification, measurement and treatment. The subjects of the study were physicians, pharmacists, physiotherapists, nurses, and nurses' aides. McAuliffe, et al. (2012) reported that education regarding pain in dementia is not routinely provided to nursing home staff. The authors concluded that there should be a focus on continuing education of professionals.

Gagnon, Hadjistavropoulos and Williams, (2013), identify that although pain focused educational programs among nurses led to positive outcomes, they are limited because of lack of financial resources and overwhelmingness of information. Both Achterberg, et al. (2013) and McAuliffe, et al. (2012) suggested that nursing staff would benefit from education in pain assessment, behavioral symptoms of pain, pharmacological treatment, pain neurophysiology and non-pharmacological treatments. Educational goals should include improving competency in distinguishing behavioral symptoms of pain from other behaviors (Achterberg, et al, 2013) and

exploring ways in which healthcare providers respond to pain once they are identified (McAuliffe, et al. 2012).

In a qualitative study of 80 emergency room nurses, Fry, Chenoweth and Arendts (2015), concluded health care providers faced many challenges in assessment and management of pain in the cognitively impaired. The authors added, "all nurses believed they had an ethical obligation to champion pain management and reduce unnecessary pain and human suffering" (p.55). In a study of 123 staff nurses in two nursing homes, Zwakhalen et al. (2007), reported that nursing staff had increased knowledge deficit about pain in dementia and educational level influenced their perceptions and knowledge. Studies have shown that healthcare providers are not adequately educated on pain assessment and management (Gagnon, Hadjistavropoulos, & Williams, 2013).

A recent systematic narrative review of 11 peer-reviewed articles was performed by Burns and Mcllfatrick (2015) and concluded that pain assessment in dementia remains difficult for healthcare providers because of "the accessibility of appropriate training…and standardized approach to pain assessment (p. 400)". Studies have shown that educational programs focusing on the identification and management of pain have demonstrated a reduction in pain scores (Bedard et al., 2006).

Also, educational programs focused on pain have been shown to be effective in improving knowledge, attitudes, and influence assessment and management of pain in patients with dementia (Long, 2016) and have the potential to impact under-assessment and under-management of pain in dementia. An educational program on pain recognition in dementia must address behavioral observations because patients with dementia may lose their ability to remember their pain, interpret the question regarding pain and may lose their ability to report the

pain themselves (Burns & McIlfarick, 2015).

Quality Improvement

Statement of Proposal /Implementation Plan

The plan, do, study, act (PDSA) (**Appendix C**) quality improvement model was be used to develop the concept of quality of the educational program to improve knowledge and beliefs of pain assessment in patients with dementia. The PDSA provides the opportunity to "determine the need for a quality change" with the development of the quality improvement question and the needs assessment to determine if the change is needed (Terry, 2015). Based on the needs assessment, the plan for the quality improvement project can be developed and implemented. As per Terry (2015, p. 239), the PDSA model is appropriate because allows for data gathered in a smaller setting to have a potential impact on a larger system. Importantly, it affords the opportunity for others interested in implementing the project to follow the well-defined format.

Stakeholders

The stakeholders included the Administrator, Medical Director, Director of Nursing, the Nurse Manager, Nurse Practitioner (DNP student), doctors, staff nurses, certified nursing assistants, physical therapists, occupational therapists, dietician and patients. The project team will include all except the patients. The Nurse Practitioner was the quality improvement coordinator. All nursing education material was provided to Director of nursing and Nurse educator (change agent).

Theoretical Framework

Tucker and Roncoroni (2015), state that a multidisciplinary, culturally sensitive model that is patient centered should be used to address the needs of the diverse patient population served and the authors recommend training for all staff and healthcare providers on delivering patient-centered, culturally sensitive care. The Plan, Do, Study, Act (PDSA) model was used to guide the clinical question, and the Relationship Based Care (RBC) Model was be used to facilitate communication and collaboration within the disciplines through a collaborative educational program.

According to Glembocki and Fitzpatrick (2013), the "Relationship-Based Care Model (RBC), provides both the philosophical foundation and the practical infrastructure to achieve organization-wide transformation in the way care and services are provided to patients and their families" (p. 19). The authors add that in the above model, "relationships are the central focus, and people from every level and area of the organization are invited to the organization's transformation" (p. 19). The RBC model will be utilized to engage all disciplines in the identification of pain in patients with dementia. Using the RBC model, nursing assistants will be as equipped as nurses and physicians in the identification of pain and will be part of the organizational transformation in utilizing an interdisciplinary approach to pain assessment in patients with dementia.

The ultimate goal is using both models is to change institutional procedure of how pain is assessed and managed in patients with dementia. The RBC model can help build staff accountability, "implement value based decision making, create collaborative relationships and assist staff to meet the holistic needs" (Glembocki & Fitzpatrick, 2013, p.430) of the patients with dementia experiencing pain. Taking on a leadership role and making a commitment to

policy development will promote quality care for this vulnerable patient population. To change the culture and decrease the disparity in pain management in patients who are cognitively impaired compared to persons who are cognitively intact, I must lead the interdisciplinary team and develop policies and procedures that can increase organizational commitment. To do so, the policies must, "enhance access to health care for diverse population groups, increase the quality and effectiveness of the care, support the cultural competence of providers of services and enable diverse health care workers to work effectively together" (Dreachslin, Gilbert & Malone, p. 127). The RBC model will be utilized to engage all disciplines in the identification of pain in patients with dementia. The resources required include healthcare providers to participate in surveys and educational program.

Methods

Project Design

A single group pretest-posttest design was used to evaluate healthcare provider's knowledge and attitudes about pain in patients with dementia.

Setting

The study was conducted at Penn Center for Rehab and Care (PCRC), a 120 long- term care and sub-acute nursing facility part of the University of Pennsylvania Health care System in Philadelphia, Pennsylvania. I am employed by the health system and practice as a nurse practitioner at PCRC. I chose this setting because pain assessment and management remains problematic.

Recruitment.

After IRB approval, health care providers in a long term care facility were recruited using flyers to announce the educational program. The flyer clearly stated participation was voluntary.

MEASURES/ **Instrument**s

Demographic data including gender, occupation, age, years of experience and hours of employment were collected.

Knowledge on pain assessment was measured using a 17- item psychometrically sound questionnaire by Zwakhalen, Hamers, Peijnenburg and Berger (2007), to obtain information on knowledge and attitudes of healthcare professionals regarding pain in dementia **(Appendix D)**.

The questionnaire is rated in a five-point Likert scale (1=completely disagree, 2= disagree to some extent, 3=no opinion, 4=agree to some extent and 5=completely agree) with scores ranging from 17-85. Higher scores indicate more knowledge in assessment of pain in dementia patients.

As per Zwakhalen et al. (2007, p. 179), "although knowledge and belief are two closely related constructs, the 17 items remaining in the final scale, with the exception of the second factor, mostly measured knowledge". The internal consistency and the Cronbach's alpha of the 17-item questionnaire was 0.782 as normed in a sample of 135 nursing staff in nursing homes (Zwakhalen et al., 2007, p. 180).

Pain assessment was measured using the Pain Assessment in Advanced Dementia (PAINAD) instrument that assesses behavioral pain in adults with cognitive impairment and limited ability to self-report (Paulson-Conger et al., 2011). The PAINAD has been found to be valid and reliable (Horgas, 2012) in patients with dementia but may not detect pain if behaviors

are less obvious (Herr et al., 2006). According to Warden et al. (2003), the tool demonstrates adequate psychometric properties and is easy to use in the nursing home setting for patients with dementia. The PAINAD has been tested in the long-term care setting (Passmore & Cunningham, 2014). It is strongly recommended that the PAINAD be utilized to standardize pain assessment in patients with dementia. Warden et al. (2003), reported that the PAINAD scale assesses five behaviors: breathing, negative vocalization, facial expression, body language, and the ability to be consoled. The PAINAD is a 5 item observational tool with an internal consistency reliability of 0.80 (Paulson-Conger et al., 2011). "Total scores range from 0-10 (based on a scale of 0-2 for 5 items, with a higher score indicating more severe pain (0="no pain" to 10="severe pain")" (Warden, Hurley & Volicer, 2003).

Educational program. The educational program was delivered in group session for 90 minutes that include training in the use of the Pain Assessment in Advanced Dementia (PAINAD). The American Society for Pain Management Nursing (2006) recommends that pain in patients who are unable to self- report should be routinely assessed, recognized and treated. The Hierarchy of Pain Assessment Techniques is recommended by the Society, including the use of the Pain Assessment in Advanced Dementia (PAINAD) behavioral pain scale (Herr et al., 2006). The recommendations for pain assessment in patients with dementia as per Herr et al. (2006) are:

- Self-Report. As per Horgas (2012), self- report may not be possible because dementia affects the central nervous system and causes deficits in language and higher cognitive processing. "As dementia progresses, the ability to self report is no longer possible (Herr et al., 2006).
- Searches for Potential Causes of Pain/ Discomfort such as recent falls or musculoskeletal

disorders.

Observation of Patients Behaviors. The American Geriatric Society (2002), recommends that when a patient cannot self -report, a behavioral assessment tool should be used.**Chart Review.** Chart review was performed 30 days after the educational program (**See Appendix E)** to determine the feasibility of the use of the PAINAD instrument by study participants.

Plan

Procedures. Needs assessment was performed during a clinical practicum, which included an evaluation of the current pain assessment and management process. A literature search was conducted to determine best practice for pain assessment in dementia. It was determined that the PAINAD tool reliability is good for interrater reliability and was easier to use given its similarities with the 0-10 Numeric Rating Scale commonly used in verbal patients.

During this phase, research of the survey and development of the educational program was completed. The educational program was based on the clinical practice recommendations by Herr et al. (2011).

The education was structured using the "Hierarchy of Pain Assessments Techniques" as outlined by Herr, Coyne, Manworren, McCafferty, Merkel, Pelosi-Kelly and Wild (2006); Horgas (2012), Assessing Pain in Older Adults educational modules and PAINAD demonstration video. The education included the implementation of the PAINAD tool.

Do

An application was filed and approved from the University of Pennsylvania and Drexel University IRBs. After IRB approval (**See Appendix F**), implementation of the quality improvement project was initiated.

A general announcement was made to all healthcare providers regarding the educational program using flyers posted throughout Penn Center for Rehab and Care **(See Appendix H).**

A questionnaire developed by Zwakhalen et. al. (2007), was administered on knowledge and beliefs before the educational program. The questionnaires were coded for anonymity and kept in locked draw.

Three 90-minute educational sessions were offered (one for each shift). The education included the use of handouts that cover knowledge about pain and pain assessment in PWD, and power-point presentation by Nurse Practitioner, and a video demonstration on the use of the PAINAD. 22 participants voluntarily attended the educational programs.

Upon completion of the educational program, with approval of the Director of Nursing, PAINAD form marked "Pilot" was place on each patient's chart by the medical records department. Extra forms were kept in the documents' drawer for new admissions. The therapy department was provided with their own supply of forms because they do not chart directly in the patients' charts.

The PAINAD was placed in the flow sheet section of every patients chart in the 120- bed facility and marked "Pilot" because it was not yet a policy. After the educational program, of the 13 participants, nine participants were instructed to start using the PAINAD: The nurses (5 RNs, 1 LPN), therapist (2) and 1 MD. The 3 CNAs and 1 RD per policy and job description do not document pain assessment.

Two weeks post educational program, participants were surveyed by using the same questionnaire by Zwakhalen et al. (2007). 13 participants who completed the first questionnaire and attended the educational program, completed the questionnaire two weeks after the educational program.

Nine study participants did not complete the posttest questionnaire. This high attrition rate is attributed to staff turnover and rotation of the therapist to another site, which was not, anticipated initially when the subjects were recruited.

Four weeks post educational program, a chart review was conducted to evaluate the use of the PAINAD and what actions relevant to pain assessment were taken.

Study

Data Analysis

Data were analyzed using descriptive statistics and t-test.

Results

Table 1 presents the demographics of the study participants. A convenience sample of 22 health care providers (nurses, certified nursing assistants, medical doctor, physical and occupational therapist, and registered dietician) met the inclusion criteria to participate in the study. Of the 22 eligible subjects, only 13 subjects completed the baseline questionnaire, attended the educational program and completed the questionnaire 2 weeks after the education. The nine subjects did not complete the post test after two weeks because of the following reasons: Three therapist rotated to another practice site, 1 RN out on maternity leave, RN on vacation, 1 RN resigned, 2 LPNs on vacation, 1 “unknown” refused to complete post-test with no reason provided.

The mean age of participants was 43, majority female with more 10 years of experience. The 13 participants included 5 RNs, 1 LPN, 3 CNAs, 1 RD, 2 therapists and 1 MD with an average of 38 hours of employment weekly.

Table 1 - Demographics of Study Participants (N=13)

Gender	**n**	**%**		
Female	12	92.3%		
Male	1	7.7%		
Occupation	**n**	**%**		
CAN	3	23.1%		
LPN	1	7.7%		
MD	1	7.7%		
OT/PT	2	15.4%		
RD	1	7.7%		
RN	5	38.5%		
Age	**n**	**%**	**Range**	**Mean**
Under 30	2	15.4%	26 - 59	43.23 (10.86)
31 – 40	2	15.4%		
41 – 50	4	30.8%		
Over 50	5	38.5%		
Years of Experience	**n**	**%**	**Range**	**Mean**
10 Years and Under	5	38.5%	0 - 32	14.43 (11.28)
11 - 20 Years	1	7.7%		
More than 20 Years	3	23.1%		
No Response	4	30.8%		
Hours of Employment	**n**	**%**	**Range**	**Mean**
Less than 40 hours	1	7.7%	20 - 45	38.85 (5.71)
40 hours of more	12	92.3%		

Table 2 presents the pre and posttest of knowledge scores. A paired t test was used to test the diference in knowledge aong health care providers from baseline (pretest) and 2 weeks after the educational program (post test).

The findings indicate that the health care providers had a low mean pretest score (32.69, SD =6.20) in knowledge on pain assessment in PWD. The mean posttest score although slightly higher at 35.23, (SD= 8.05) also showed low knowledge among health care providers in pain assessment on PWD. The findings showed no significant difference (t=(12)=1.16; p=0.27) between the pretest and post test scores on knowledge on pain assessment in PWD. These results suggest that the educational program did not have a positive impact on improving knowledge. Possible reasons for the lack of significant findings in this study may be attributed to the small sample size (N=13), the use of a convenience sample, and the possibility that increasing knowledge in pain assessment of PWD may require longer than 2 weeks.

Table 2 - Paired t-test on Knowledge Scores (N=13)

	Paired Differences (n=13)				
	Mean	**Std. Deviation**	**Std. Error Mean**	**t**	**Sig. (2-tailed)**
Pre	32.69	6.20	1.72		
Post	35.23	8.05	2.23		
Mean Difference	2.54	7.91	2.19	1.16	0.27

Table 3 presents descriptive statistics on knowledge on pain assessment in dementia. With this population, the Cronbach's alpha pretest (0.698) demonstrates acceptable reliability. The Cronbach's alpha posttest (0.75) demonstrates better reliability.

Table 3 - Descriptive Statistics of the Study Variable (N=13)

		Range	Mean	St Dev	Alpha Cronbach
Knowledge Questionnaire	Pretest	26 – 38.8	32.69	6.2	0.698
	Posttest	27-43.7	35.69	8.05	0.75

Act

Evaluation

The expected outcomes of the educational quality improvement intervention were improvement in knowledge and attitudes regarding pain assessment in dementia and implementation of the PAINAD.

To assess the feasibility of implementing a standardized pain assessment tool in dementia in the long-term care setting, a chart review was conducted in 30 days after the educational program to evaluate the use of the PAINAD.

The PAINAD was placed in the flow sheet section of every patients chart in the 120 bed facility and marked “Pilot” because it was not yet a policy. After the educational program, of the 13 participants, nine participants were instructed to start using the PAINAD: The nurses (5 RNs, 1 LPN), therapist (2) and 1 MD. The 3 CNAs and 1 RD per policy and job description do not document pain assessment.

An unexpected challenge was the nurse educator who was supposed to champion the implementation of the PAINAD by monitoring the use of the PAINAD as a pain assessment tool, resigned the week of the educational program. The RNAC was “too busy” to reinforce the use of the tool. The nurse manager was also on vacation for 2 weeks during the implantation period.

The absence of an electronic medical record system also made the chart review difficult. For the above reasons, the chart review (**Appendix E**) was performed on 20 charts of patients with known history of moderate to severe dementia (Mini-mental state exam of 20 or less). All 20 charts had PAINAD forms in the flow sheet section.

Table 4 presents the chart review results on the implementation of the PAINAD:

Of the 20 charts reviewed, only 2 charts had PAINAD scores completed by 2 RNs (40%) out of the 5 nurses who participated in the study. The PAINAD scores were 5 and 8 indicating that patients were in moderate and severe pain.

In an attempt to act on what's learned based on the PDSA model, a meeting was held to discuss results with the stakeholders. At the meeting, the therapy department provided 127 completed PAINADs with 55 (23%) being completed by the 2 therapists (100%) who participated in the program. The lead therapist explained that the forms were not kept on the chart because therapy does not document directly in the chart. In an effort to keep the data as clean as possible, only the PAINADs completed on patients with moderate to severe dementia were included. Of the 55 PAINADs completed by the 2 therapists, 5 (9%) of those patients had a diagnosis moderate to severe dementia. The pain scores for the 5 patients with dementia were documented as 2 (1-mild pain), 2 (3-mild pain) and 1 (6-moderate pain).

Because the nurses documented in the chart, it was more feasible to determine what actions the nurses took based on the pain scores. 1 nurse reported pain score of 5 (moderate pain) and pharmacological intervention of Tylenol provided. The other nurse reported pain score of 8 (severe pain) with pharmacological intervention of tramadol. Interestingly, for nursing, only pharmacological action (100%) was documented based on the PAINAD scores.

The therapists wrote in their actions on the actual PAINAD tool. The therapists documented non-pharmacological interventions on all 5 assessments (100%). Although, only non-pharmacological actions were documented by the therapists, it cannot be ruled out that the therapist notified the nurse or doctor for the patient who then managed the pain pharmacologically.

The chart review was challenging because the documentation was not all in one place. he The lack of EMR and limited time frame of the were also challenges.

Table 4-Implementation of the PAINAD Scale

Participants	Met study inclusion	Implemented PAINAD	%	PAINAD scores	Action
RN	5	2	40%	5-moderate pain 8-moderate pain	Pharmacological Pharmacological
LPN	1	0	0%		
MD	1	0	0%		
PT/OT	2	2	100%	1-mild 1-mild 3-mild 3-mild 6-moderate	NP NP NP NP NP

NP (non-pharmacological); 1-3 (mild pain);(4-6) moderate pain; 7-10(severe pain)

Human Subject Protection

This quality improvement project posed no identifiable risks to human subjects. Identifiable patient data was not used. The subjects recruited were healthcare providers (nurses, doctors, certified nursing assistants, physical therapist and occupational therapists). The participation is voluntary. An application to the University of Pennsylvania and Drexel University IRBs were filed for expedited review. Identifiable patient information was not used for chart review.

Strengths and Limitations

There was strong, interdisciplinary support for the quality improvement project with the anticipated impact on the MDS and the administrator continues to support pain management improvement efforts. The stakeholders verbalize the importance of improving knowledge and attitudes on pain assessment in dementia, standardizing pain assessment to improve pain management that may lead to decreased pain reports on the MDS. The RNAC was the most enthusiastic and was supposed to champion the project but did not "have time" to do so.

The sample size was small and the attrition rate was high. With an effect size of .5 and power of .8, 34 participants would have been needed to show a difference. A repeated measures deign would have allowed for data to be collected over a longer period of time, allowing for the therapist to rotate back to the site and for the nurses to return from leave and vacation. However, even with this design, the original sample was still small at 22.

The greatest limitation was that the nurse educator resigned the week of the educational program. Because I am not directly employed by the facility, it was difficult to monitor and sustain the change without a nurse educator and the RNAC championing.

The limitation of the questionnaire is that healthcare providers may have responded "in ways that reflect best practice rather than they actually do" (Burns & McIlfatrick, 2015, p. 486). Also the questionnaire mainly measured knowledge.

Another limitation is that not all documentation is in the chart and Penn Center does not yet have electronic medical record to facilitate chart review.

The project also had a small number of participants. Because participation was voluntary and there was no incentive besides free lunch to participate, only 13 persons completed the pretest, participated in the educational program and completed the posttest.

An unforeseen limitation was the rotation of therapist to another site, which also affected sample size.

A major weakness of the chart review was that it was not based on the actual subjects of the study. To properly evaluate the feasibility of implementation, charts with completed PAINADs by the subjects of the study should have been chosen for review.

Conclusion and Implications

The findings showed no significant difference in the pre and post tests knowledge of health care providers on assessment of pain in PWD after 2 weeks of the implementation of an educational program. Knowledge on assessment of pain in PWD was low indicating the need to provide educational programs to enhance knowledge among health care providers if the goal is to improve quality of life of patients in long term care facilities. There is a need to provide periodic education program with booster sessions to staff on pain assessment in dementia.

Although there was no significant change in knowledge on pain assessment among health care providers, four (30%) of study participants (2 RNs and 2 (PTs) implemented the use of

PAINAD tool in their patient care. The availability of the PAINAD scale to staff seems to enhance the use of a standardized tool to assess pain in PWD in this facility.

Improving knowledge and attitudes about pain in dementia and implementation of the PAINAD shows some promise to early recognition and assessment of pain. This is an area that needs continued research. The implementation of the PAINAD must be championed by the nurse educator or a nurse leader at the facility for the change to be sustained.

Adopting the PAINAD in the long-term care setting will improve care because it corresponds well with the Minimum Data Set (Herr et al., 2006). Ensuring and incorporating regular use of the tool through consistent policies and procedures that guide pain assessment practices can help sustain the change.

A policy for evaluating the presence of pain in patients with dementia should be instituted across the health system including PCRC.

"The quality improvement project requires change at the microsystem level" (Terry, 2015). Patients with dementia who are experiencing pain will be served by the microsystem. This long term care facility serves a larger health system. It receives patients from across the United States and must have a standardized pain management program for it's most vulnerable population. The ultimate goal is to implement a pain policy in dementia to pain assessment and management. The change will impact not only the facility but also the Department of Geriatrics in the health system.

Incidentally or not, the facility's MDS facility pain quality measure decreased to 52.4 as of 8/17/2016 from 59.8% in May 2016.

Recommendation for practice is that pain assessment in PWD be continued as an ongoing educational program and a behavioral pain assessment tool should be used to assess pain in

patients with dementia who are unable to self- report. Pain assessment in dementia remains challenging and further research is needed to improve pain assessment in patients with dementia.

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Appendix A

Gap Analysis

Current Experience	Planned Interventions	Desired Outcome	Gap Identified
Pain in patients with dementia is under-recognized and undertreated. Pain data on MDS is triggered for patients with moderate to severe dementia. There is no standardized pain assessment tool for patients with dementia. There is no standardized pain treatment guideline for patients with dementia.	Healthcare professionals will be educated through a collaborative educational program	Pain assessment in patients with dementia will be promptly recognized, assesses, documented and treated.	Nurses and doctors have a knowledge deficit of pain assessment in patients with dementia. Pain assessment is performed inconsistently by nursing staff and doctors

(Terry, 2015)

Appendix B

Pain Assessment in Advanced Dementia (PAINAD) Scale

Items*	0	1	2	Score
Breathing independent of vocalization	Normal	Occasional labored breathing. Short period of hyperventilation.	Noisy labored breathing. Long period of hyperventilation. Cheyne-Stokes respirations.	
Negative vocalization	None	Occasional moan or groan. Low-level speech with a negative or disapproving quality.	Repeated troubled calling out. Loud moaning or groaning. Crying.	
Facial expression	Smiling or inexpressive	Sad. Frightened. Frown.	Facial grimacing.	
Body language	Relaxed	Tense. Distressed pacing. Fidgeting.	Rigid. Fists clenched. Knees pulled up. Pulling or pushing away. Striking out.	
Consolability	No need to console	Distracted or reassured by voice or touch.	Unable to console, distract or reassure.	
Total**				

*Five-item observational tool (see the description of each item below).

**Total scores range from 0 to 10 (based on a scale of 0 to 2 for five items), with a higher score indicating more severe pain (0="no pain" to 10="severe pain").

Breathing

1. Normal breathing is characterized by effortless, quiet, rhythmic (smooth) respirations.
2. Occasional labored breathing is characterized by episodic bursts of harsh, difficult or wearing respirations.
3. Short period of hyperventilation is characterized by intervals of rapid, deep breaths lasting a short period of time.
4. Noisy labored breathing is characterized by negative sounding respirations on inspiration or expiration. They may be loud, gurgling, or wheezing. They appear strenuous or wearing.
5. Long period of hyperventilation is characterized by an excessive rate and depth of respirations lasting a considerable time.
6. Cheyne-Stokes respirations are characterized by rhythmic waxing and waning of breathing from very deep to shallow respirations with periods of apnea (cessation of breathing).

Negative vocalization

1. None is characterized by speech or vocalization that has a neutral or pleasant quality.
2. Occasional moan or groan is characterized by mournful or murmuring sounds, wails or laments. Groaning is characterized by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
3. Low level speech with a negative or disapproving quality is characterized by muttering, mumbling, whining, grumbling, or swearing in a low volume with a complaining, sarcastic or caustic tone.
4. Repeated troubled calling out is characterized by phrases or words being used over and over in a tone that suggests anxiety, uneasiness, or distress.
5. Loud moaning or groaning is characterized by mournful or murmuring sounds, wails or laments much louder than usual volume. Loud groaning is characterized by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.

6. Crying is characterized by an utterance of emotion accompanied by tears. There may be sobbing or quiet weeping.

Facial expression

1. Smiling is characterized by upturned corners of the mouth, brightening of the eyes and a look of pleasure or contentment. Inexpressive refers to a neutral, at ease, relaxed, or blank look.
2. Sad is characterized by an unhappy, lonesome, sorrowful, or dejected look. There may be tears in the eyes.
3. Frightened is characterized by a look of fear, alarm or heightened anxiety. Eyes appear wide open.
4. Frown is characterized by a downward turn of the corners of the mouth. Increased facial wrinkling in the forehead and around the mouth may appear.
5. Facial grimacing is characterized by a distorted, distressed look. The brow is more wrinkled as is the area around the mouth. Eyes may be squeezed shut.

Body language

1. Relaxed is characterized by a calm, restful, mellow appearance. The person seems to be taking it easy.
2. Tense is characterized by a strained, apprehensive or worried appearance. The jaw may be clenched (exclude any contractures).
3. Distressed pacing is characterized by activity that seems unsettled. There may be a fearful, worried, or disturbed element present. The rate may be faster or slower.
4. Fidgeting is characterized by restless movement. Squirming about or wiggling in the chair may occur. The person might be hitching a chair across the room. Repetitive touching, tugging or rubbing body parts can also be observed.
5. Rigid is characterized by stiffening of the body. The arms and/or legs are tight and inflexible. The trunk may appear straight and unyielding (exclude any contractures).
6. Fists clenched is characterized by tightly closed hands. They may be opened and closed repeatedly or held tightly shut.
7. Knees pulled up is characterized by flexing the legs and drawing the knees up toward the chest. An overall troubled appearance (exclude any contractures).
8. Pulling or pushing away is characterized by resistiveness upon approach or to care. The person is trying to escape by yanking or wrenching him or herself free or shoving you away.
9. Striking out is characterized by hitting, kicking, grabbing, punching, biting, or other form of personal assault.

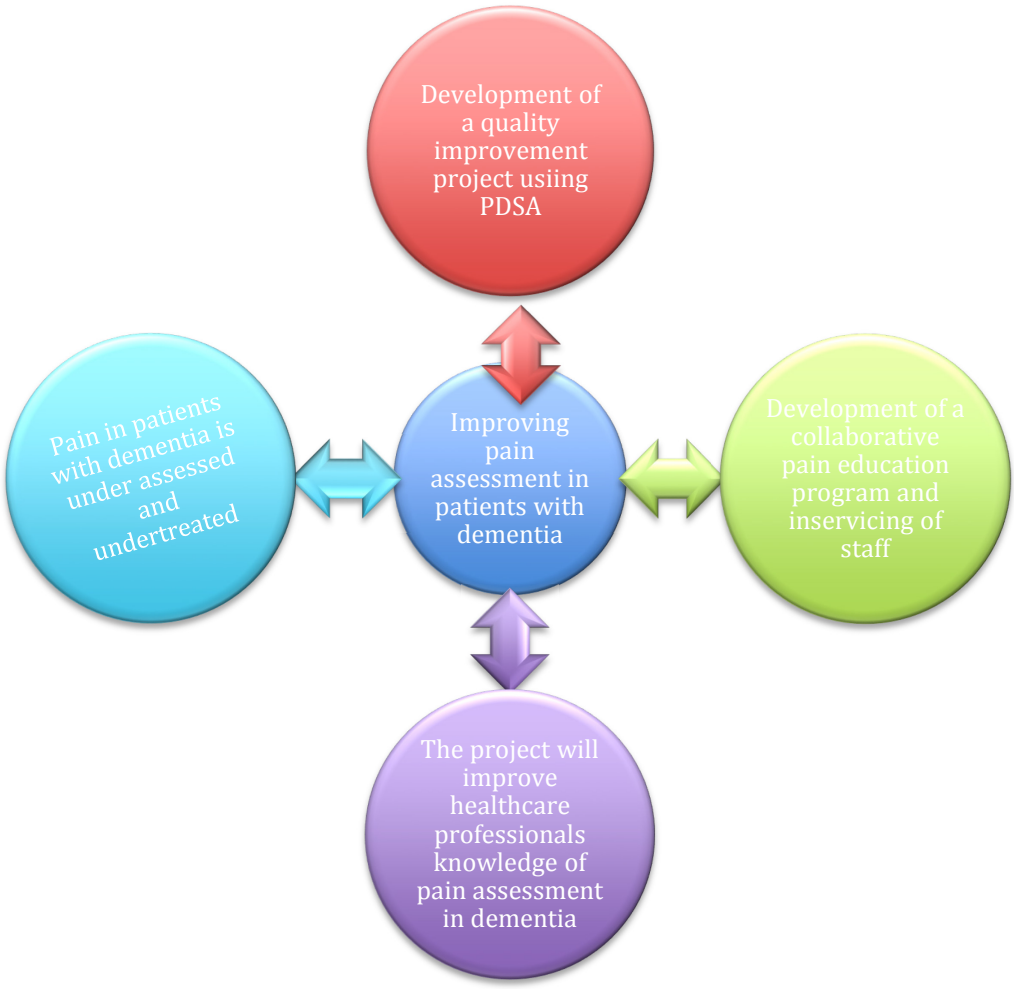
Consolability

1. No need to console is characterized by a sense of well-being. The person appears content.
2. Distracted or reassured by voice or touch is characterized by a disruption in the behavior when the person is spoken to or touched. The behavior stops during the period of interaction with no indication that the person is at all distressed.
3. Unable to console, distract or reassure is characterized by the inability to sooth the person or stop a behavior with words or actions. No amount of comforting, verbal or physical, will alleviate the behavior.

Warden et al. (2003)

Appendix C

Diagram Depicting the System Before and After the Proposed Intervention



Zwakhalen et al. (2007)

Appendix D

You are being asked to participate in a quality improvement project to improve health care providers' knowledge and attitudes towards pain assessment in patients with dementia.

By coming to this educational program and completing this questionnaire, you are consenting to participate in this quality improvement project. Participation is completely voluntary. The questionnaire will take approximately take 10 minutes to complete. Your decision whether or not to participate in the project will not affect your employment or your relationship with the University of Pennsylvania Health System, administrators, other health care providers, etc.

1. **Name:**
2. **Age:**
3. **Gender:**
4. **Job Title:**
5. **Years of formal education:**
6. **Ethnic affiliation:**
7. **Hours of employment per week:**
8. **Years of Experience:**

	Completely disagree	Disagree to some extent	No opinion	Agree to some extent	Completely agree
1. Older people experience pain less intensely than younger people					
2. Pain medication works best in young people than in the elderly					
3. Pain medication works longer in the elderly than in young people					
4. Pain medication has more side effects in the elderly than in young younger people					
5. Dementia patients experience less pain than nondementia patients					
6. Assessing pain in a dementia patient is a matter of guessing					
7. Where I work, pain is assessed correctly					
8. Where I work, pain is treated correctly					

9. Where I work, much attention is given to pain in dementia patients					
	Completely disagree	**Disagree to some extent**	**No opinion**	**Agree to some extent**	**Completely agree**
10. Pain medication should only be administered to patients suffering from severe pain					
11. Patients are often prescribed too much pain medication					
12. It is better to administer pain medication when necessary, rather than according to a fixed schedule					
13. Administering pain medication should be postponed as long as possible, because dementia patients should receive as little pain medication as possible					
14. A dementia patient should first report pain before receiving next dose of pain medication					
15. Pain is part of the aging process					
16. Older people are affected by pain more often than younger people					
17. Pain medication, if administered in large quantities, easily leads to addiction among the elderly					

Questionnaire responses will only be accessible by *Johanne Louis*. If you have questions about the study or your rights as a research participant, please feel free to contact me at 215-301-7171. If you have any concerns or complaints, you may contact the Office of Regulatory Affairs at the University of Pennsylvania 215-898-2614.

Appendix E

Chart Review Checklist
Chart Review 30 days after educational program

Chart Review: No identifiable patient data. 20 charts of patients with known history of moderate to severe dementia on long-term care unit

Chart #	Was Pain documented using PAINAD? Yes/NO	Was there any action taken related to pain assessment? Yes/no	If yes, 1=pharmacological 2=nonpharmacological
1			
2			
3			
4			
5			
6			
7			
8			
9			
10			
11			
12			
13			
14			
15			
16			
17			
18			
19			
20			

Appendix F

Drexel UNIVERSITY
Office of Research

APPROVAL OF PROTOCOL

August 5, 2016

Elizabeth Gonzalez
Drexel University
CNHP – Doctoral Nursing Program

Dear Dr. Gonzalez,

On August 5, 2016 the IRB reviewed the following protocol:

Type of Review:	Initial
Title:	Improving Healthcare Provider`s Knowledge and Attitudes about Pain Assessment in Dementia
Investigator:	Elizabeth Gonzalez
IRB ID:	1607004722
Funding:	Internal
Grant Title:	None
Grant ID:	None
IND, IDE or HDE:	None
Documents Reviewed:	Request for Letter of Determination of Non-Human Subject Research

The IRB determined that the proposed activity is not research involving human subjects as defined by DHHS and FDA regulations.

IRB review and approval by this organization is not required. This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these activities are research involving humans in which the organization is engaged, please submit a new request to the IRB for a determination.

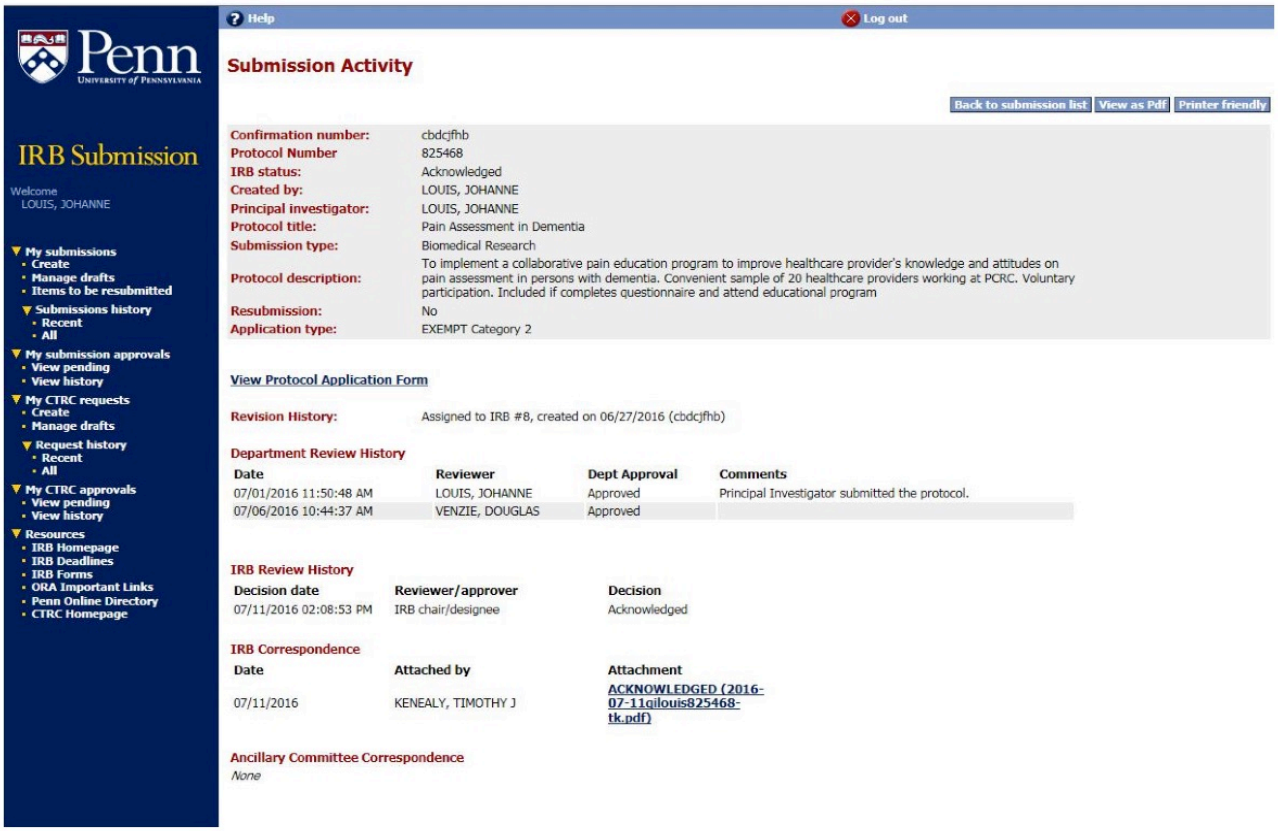
Sincerely,

Lois Carpenter

Digitally signed by Lois Carpenter
DN: cn=Lois Carpenter, o=Drexel University, ou=Human Research Protection, emailAddress=lac57@drexel.edu, c=US
Date: 2016.08.05 13:47:05 -04'00'

Lois Carpenter
IRB Coordinator
Human Research Protection

Appendix G


Penn
University of Pennsylvania
IRB Submission
Welcome
LOUIS, JOHANNE
My submissions
Create
Manage drafts
Items to be resubmitted
Submissions history
Recent
All
My submission approvals
View pending
View history
My CTRC requests
Create
Manage drafts
Request history
Recent
All
My CTRC approvals
View pending
View history
Resources
IRB Homepage
IRB Deadlines
IRB Forms
ORA Important Links
Penn Online Directory
CTRC Homepage
Help
Log out
Submission Activity
Back to submission list
View as Pdf
Printer friendly
Confirmation number: cbdcjfhb
Protocol Number 825468
IRB status: Acknowledged
Created by: LOUIS, JOHANNE
Principal investigator: LOUIS, JOHANNE
Protocol title: Pain Assessment in Dementia
Submission type: Biomedical Research
Protocol description: To implement a collaborative pain education program to improve healthcare provider's knowledge and attitudes on pain assessment in persons with dementia. Convenient sample of 20 healthcare providers working at PCRC. Voluntary participation. Included if completes questionnaire and attend educational program
Resubmission: No
Application type: EXEMPT Category 2
View Protocol Application Form
Revision History: Assigned to IRB #8, created on 06/27/2016 (cbdcjfhb)
Department Review History
Date Reviewer Dept Approval Comments
07/01/2016 11:50:48 AM LOUIS, JOHANNE Approved Principal Investigator submitted the protocol.
07/06/2016 10:44:37 AM VENZIE, DOUGLAS Approved
IRB Review History
Decision date Reviewer/approver Decision
07/11/2016 02:08:53 PM IRB chair/designee Acknowledged
IRB Correspondence
Date Attached by Attachment
07/11/2016 KENEALY, TIMOTHY J ACKNOWLEDGED (2016-07-11qilouis825468-tk.pdf)
Ancillary Committee Correspondence
None

Appendix H

Pain Assessment in Dementia Educational Program

Penn Center for Rehab and Care, 1st floor Room 165
3609 Chestnut Street, • Philadelphia
July 12, 2016 6am/12pm/6pm
For All Healthcare Providers

This educational program is a part of quality improvement project to improve healthcare provider's knowledge and attitudes about pain assessment in dementia.
By coming to this educational program and completing the questionnaire, you are consenting to participate in the above quality improvement project.
Participation is voluntary.
Any questions please contact Johanne Louis 267-693-3947.

Johanne Louis, CRNP